

European Medicines Regulatory Network (EMRN) workshop on Geographic Atrophy endpoints

Patients Perspective

Avril Daly, CEO, Retina International

EMRN workshop on Geographic Atrophy endpoints – 29 April 2026



Retina
International

Disclosure statement

The views and opinions expressed in the following PowerPoint slides are those of the individual presenter and should not be attributed to any organization with which the presenter is employed or affiliated.

Retina International



- **Empower**
We equip our members with the knowledge, connections, and confidence to represent the patient voice and shape decisions.
- **Advocate**
We bring a united global retina patient voice to the tables where policy and access decisions are made.
- **Innovate**
We drive research forward to reflect the real, holistic needs of people living with retinal conditions.

Prevalence of Geographic Atrophy (GA)

- Globally, the prevalence of GA ranges from 0.10% to 3.7% in people over 50 years of age
 - 5 million people living with GA
 - Depends on the geography and age range
 - Europeans have higher prevalence as compared to Asians or Africans
 - Prevalence increases with increasing age
- The prevalence of GA in people with European Ancestry is estimated at 0.04% (50 years of age) to 11.30% (90 years of age)

Vangsted et al, 2023, Vujosevic et al, 2023, Rudnicka et al, 2012, Wong et al, 2014

The Impact of GA

Living with GA

Loss of Central Vision, Contrast Sensitivity, Dark Adaptation

Loss of Independence

Anxiety, Depression, Fear, Anger,
Frustration

Impact on Daily living activities –
Reading, Hobbies, Social Interaction,
face recognition, driving

Productivity loss

Job loss

Job reduction

Impact on caregivers

Caregiver job loss

Caregiver job reduction

Loss of leisure time of caregivers

Loss in Quality of Life – NEI-VFQ 25 Composite Score - 64.4 (range 47 – 81*)

42% to 49% higher risk of falls and 33% to 45% higher risk of fractures (bilateral GA, sub-foveal involvement)

Higher all-cause mortality vs intermediate AMD/nAMD/no AMD

Nielsen et al, 2023, Patel et al, 2020, Paudel et al, 2024, Ahluwalia et al, 2021, Hu et al, 2025, Sivaprasad et al, 2019, Bakri et al, 2024

***Unilateral GA**

The Economic Burden of GA

- Lack of global studies on Economic burden of GA
- European study – Bulgaria and Germany – RI
 - Annual cost for GA
 - € 220.54 Million – €19,490 per person (Bulgaria)
 - € 3.73 Billion - €19,511 per person (Germany)
 - In both Bulgaria and Germany
 - 87% of the total cost was incurred due to impact on wellbeing (loss in quality of life due to anxiety and depression)
 - 1- 1.6% Direct Medical costs, 4% Indirect medical costs, 7 - 8.5% Productivity cost

The profound humanistic and economic burden highlight the urgent need to develop effective treatments and meaningful support for people living with GA

What do patients living with GA want?

- Top 10 treatment expectations of Current and Potential Therapies for GA – Study conducted among patient leaders from patient driven retinal research funding and patient support organizations
- 1) ***Stability of Vision** 2) **Ability to recognize faces** 3) **One time therapy** 4) **Oral Administration** 5) **Improvement in Vision** 6) **Independent mobility** 7) **Intravitreal Injections** 8) **Delay further loss of vision** 9) **Ability to read** 10) **Ability to drive**

Up to 82% of UK-based patients with GA could find intravitreal therapy acceptable under the assumption that the therapy results in functional vision benefits.

Paudel et al, 2025, Dinah et al, 2025, Caswell et al, 2021, Enoch et al, 2022

“We have already had treatments that slow wet macular degeneration for almost 20 years, and we are eagerly awaiting a treatment to slow or treat dry macular degeneration. We all know that recent therapies exist in the United States and Japan, and we hope that we can also be treated quickly in Europe and France.”

78/F living with GA, Paris, France

Retina patient community consensus on endpoints (Community meetings, networking)

- Therapies must be approved based on improvement/preservation of outcome measures that reflect real-world activities – e.g., reading, mental health, mobility, facial recognition
- Outcome measures must be assessed using functional vision tests and/or patient-reported outcomes that have a strong association with activities of daily living

Key message – patients perspective

- Geographic Atrophy (GA) is a prevalent, age-related condition currently affecting an estimated over 1 million people in Europe, with prevalence expected to rise as the population ages.
- The impact of GA extends beyond vision loss, profoundly affecting patients' overall quality of life particularly mental health and incurring billions of euros in societal costs.
- People living with GA expect stability/preservation of their vision, an improved ability to perform activities of daily living, and a reduction in injection frequency from current and emerging therapies.
- Patients believe that outcome measures used in pivotal clinical trials must reflect real world activities
- The majority of people living with GA are receptive of intravitreal injections, provided the treatment delivers patient perceived functional benefit.
- Holistic care pathways that support mental health and mitigate productivity loss must be developed in parallel with novel therapeutics.

Patient and caregiver experiences

- I was 63 when I was diagnosed with AMD. It took me years to recover from this blow. Accepting the decline of vision, and the loss of autonomy that comes with it, is not easy. As a grandmother, the fact that I can no longer recognise the faces of loved ones is one of the hardest parts. **78/F, Patient living with GA, Paris, France**
- I had to give up playing the piano, which was very important and nourishing for me, especially playing chamber music in the group, because I could not read the sheet music anymore. My independence was shaken. I had to abandon driving the car. I could not participate in special educational programs outside of town or attend festivals. This really frightened me a lot. And I asked myself.: “How can I manage my daily life in the future?” I used to be an independent woman and suddenly I was dependent on others. My freedom of movement was limited, e.g. to handle technical devices in the house and garden and in public life. AMD happens when you are getting older anyway and then the vision loss comes on top. You must adapt and learn to do things in a different way, that you were used to do all your life. Fortunately, the vision loss progresses slowly, so that I was able to get used to it, but it is a hard job. Today, I am legally blind. **79/F, Patient living with GA, Hamburg, Germany**
- We are constantly concerned that something will happen (fall, deterioration of vision). It is a great responsibility. We need to be available constantly. **GA Caregiver/F, Germany**
- My top three most difficult aspects of providing care for someone living with GA is the need for constant care, lack of time and anxiety. **GA Caregiver/F, Bulgaria**

Thank you

Back-up - References

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